

TESTIMONY

Before

**United States House of Representatives
House Committee on Oversight and Government Reform
Subcommittee on Government Management, Organization, and Procurement**

By

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9/11 Health Effects: Federal Medical Monitoring and Treatment of Residents
and Responders**

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Chairman Towns, Ranking Member Bilbray, and other Members of the Government Management, Organization and Procurement Subcommittee of the Committee on Oversight and Government Reform: thank you for inviting me to testify today.

My name is Robin Herbert, MD. I am an Associate Professor in the Department of Community and Preventive Medicine of the Mount Sinai School of Medicine, and have served alongside Dr. Stephen Levin as Medical Co-Director of the Mount Sinai Center for Occupational and Environmental Medicine since 1990, and also as Co-Director of the World Trade Center Worker and Volunteer Medical Screening Program and the World Trade Center Health Effects Treatment Program at Mount Sinai. I currently serve as the Director of the World Trade Center Medical Monitoring Program Data and Coordination Center at Mount Sinai.

Having recently marked the fifth anniversary of September 11th, it is a fitting time to review what we have learned so far about the devastating acute and long-term health impacts of that day. In light of our growing understanding of the health consequences of the September 11th terrorist attacks on the nation, which affect thousands of Americans – both in the New York metropolitan area and nationally – this is also an apt time to take stock of how well we, as a nation, are caring for World Trade Center responders and others who have fallen ill or may become ill in the future.

It is estimated today that well over 50,000 people worked or volunteered in the aftermath of the attacks in and around the World Trade Center area, and the Staten Island landfill. These included traditional first responders such as firefighters, paramedics, and law enforcement officers, as well as a large and very diverse population of heavy machinery operators, laborers, ironworkers and others from the building and construction trades, telecommunication workers, transportation workers, sanitation workers and volunteers, and others from the public and private sectors. A grateful nation celebrates these men and women as heroes. However, unfortunately, during the course of their selfless work, WTC responders were exposed to a complex mix of toxic chemicals, physical hazards, and extreme psychological trauma which have resulted in well-documented upper and lower respiratory and mental health consequences as well as chronic sequelae of injuries.

In September 2006, we released a paper in the medical journal *Environmental Health Perspectives*, detailing the findings from federally funded examinations of 9,442 WTC responders whom we and our partner institutions had examined between July 2002 and April

2004. I have appended this study for your review, and I would like to direct your attention to a few key findings:

- Among these responders, 69% reported experiencing new or worsened respiratory symptoms while engaged in their efforts in or near Ground Zero.
- At the time of examination, up to 2 ½ years after the start of the rescue and recovery effort, 59% were still experiencing a new or worsened respiratory symptom, a finding which suggests that these conditions may be chronic and require ongoing treatment.
- Rates of both upper and lower respiratory symptoms remained higher than expected, even among responders who began working on or after October 1, 2001.

One of the most worrisome findings was the increased rate of breathing test abnormalities when compared with the general U.S. population. In non-smoking patients from our study we found five times more people than expected to have an abnormally low forced vital capacity, or FVC. A low FVC can be caused by a variety of conditions, including asthma with “air trapping”, large body mass, and interstitial lung diseases (scarring diseases of the lungs) of the sort that have resulted in known fatalities among a few WTC responders.

Our findings are consistent with the results of other federally funded programs designed to screen WTC responders for disease. Given what we now know about health consequences of the WTC disaster, regular monitoring/screening examinations for the lifetime of the responder population is essential for the early detection and treatment of these and other potentially devastating diseases. WTC responders were exposed to a broad array of toxins including asbestos, volatile organic compounds, PCBs, dioxins, and pulverized concrete, some of which can cause various cancers and other longer term as well as short-term chronic and severe conditions. Unfortunately, we do not know the complete range of chemicals to which responders were exposed, nor the potential health effects of the combined exposures they sustained. Thus, it has been imperative to develop approaches to the medical care of responders that are linked to disease surveillance efforts and to specialized treatment. By offering standardized, comprehensive examinations designed to identify possible WTC related physical and mental health consequences of the disaster, we can screen to find diseases early and improve health by initiating treatment early. Additionally, we can gather composite information on the health impacts of the disaster so that we can identify disease patterns early. Early identification of disease patterns will provide knowledge that will be critical to the responders themselves, because it can be used to target screening examinations to identify emerging diseases with the goal of providing early diagnosis for the responders. Dissemination of information derived from

disease monitoring in screening and treatment can then be used to improve treatment of WTC related illnesses. The ultimate goal is to prevent death and disability and to improve quality of life for those who gave so much. We greatly appreciate the federal funding that has been provided to date, which is supporting this model by funding screening/monitoring examinations and follow up testing and treatment.

In April 2002, the Mount Sinai Medical Center received funding to establish the World Trade Center Worker and Volunteer Medical Screening Program in response to growing concern about health effects among WTC responders. The Screening Program was operated as a consortium of regional Centers of Excellence and a national program that provided uniform, free, comprehensive screening examinations for WTC responders. These examinations, focused on identifying possible WTC-related physical and/or mental health conditions. The Screening Program expanded to become the World Trade Center Medical Monitoring Program in July 2004 thanks to additional federal funding. This funding will allow for screening examinations for responders every 18 months until 2009, at which time the program will come to an end unless federal funding is renewed.

Thanks to this federal support, over 20,000 WTC responders have received an initial medical screening exam to date through the Mount Sinai-coordinated consortium of occupational medicine providers. While the majority of responders examined reside in the New York/ New Jersey metropolitan area, a number of responders also hail from across the country. Indeed, responders came from as far away as California to assist in the rescue and recovery effort. Even now, over five years since 9/11, about 400 new participants register to receive baseline screening examinations each month. Thanks to federal support, over 7,250 responders have also received at least their first follow-up or comprehensive monitoring examination.

Presently, responders found to have possible WTC related physical or mental health consequences are referred immediately into the Specialized WTC Treatment Program arm of the Medical Monitoring and Treatment Program. Until November 2006, these treatment programs were sustained only by generous but limited philanthropic funding. This federal funding has been a major boon to the WTC responder population by allowing the Treatment Programs to expand services and, at Mount Sinai alone, bring in an astounding 100 new patients per month. However, as you are also likely aware, that funding is likely to run out, before the end of this fiscal year. Federal funding for the first five years, of a 20 to 30 year medical monitoring program, is scheduled to likewise run out by July of 2009.

The findings from the Medical Monitoring Program are underscored by the spectrum of disease seen among responders attending the Treatment Program arms of the New York/ New

Jersey consortium clinical centers. The most common conditions seen among responders in treatment to date more than echo those seen in the larger Monitoring Program population. Mount Sinai's WTC Health Effects Treatment Program is the largest of the five Consortium Clinic Treatment Programs and has provided medical services for some 2,800 patients to date, as well as social work services provided to some 2,200 patients. (There is substantial overlap between these two populations). Of treatment program patients seen from August 2006 to December 2006:

- 86% were diagnosed with an upper respiratory condition, such as chronic sinusitis;
- 51% were diagnosed with a lower respiratory condition, such as asthma and WTC cough;
- 32% were diagnosed with a gastrointestinal condition, predominantly gastroesophageal reflux disease;
- 29% were diagnosed with a musculoskeletal condition, often the result of an injury sustained while working on "the pile"; and
- 38% were diagnosed with a mental health condition, including PTSD, anxiety, or depression in addition to their physical ailments.

Sadly, most patients seen in the program suffer from multiple WTC-related conditions. This complicates the management of their conditions, as well as their access to certain benefits like Workers' Compensation. Indeed, access to adequate healthcare has been a major problem for many Mount Sinai Treatment Program patients. More than 44% of our patients are uninsured. An additional 23% are underinsured. The Treatment Program patients comprise a particularly vulnerable population – one that is in need of a comprehensive program that provides medical and mental health coverage, is available in their native language, and is not reliant on private insurance. For our patients, the services provided through philanthropic and federal funds have been a lifeline, and the importance of this program will only increase with the passage of time and the potential emergence of disease.

Since the inception of the World Trade Center Worker and Volunteer Medical Screening Program, the first federally funded screening program established by Mount Sinai in April 2002, and a parallel program established by New York City's Fire Department, it has been clear how the existence of these programs have benefited responders as an appropriate national response and one critically necessary to operate well into the future.

- The benefits of and need for appropriate diagnosis of and treatment for WTC-related conditions based on the collective experience of occupational and environmental medicine specialists has been established.

- The benefits of developing the programs based on the direct input of the affected populations, including organized labor, is established.
- The need for treatment with no out-of-pocket cost for those affected is established.
- The need for long-term medical monitoring is established.
- The need for an active system of disease tracking and surveillance in order to identify and treat emerging diseases while they are still treatable is established.

Our program has been designed and implemented to provide the greatest benefits and meet the demonstrated needs of our patient population. We believe that our program, and the lessons we have learned in the wake of September 11th, should help guide future disaster response.

The programs provide a comprehensive, standardized approach to providing the physical and mental health monitoring and treatment so desperately needed by WTC responders. Just as importantly, the clinical data collected and aggregated from these clinical programs provides an opportunity to come to a scientific understanding of the health effects of the horrific exposures sustained in the months following the terrorist attacks. This information benefits not only participants of our program, but also others who may not be eligible to participate in this or any monitoring and treatment program, in that it can guide the care provided by healthcare professionals across the country.

From the beginning, the FDNY and NY/ NJ Clinical Consortium programs have worked together to ensure that all responders receive the same standard of care. As we move forward, plans are already underway to allow for the expansion and integration of the existing Treatment Programs into the Monitoring Program. This integration affords patients streamlined access to high quality, standardized diagnostic and treatment services with clinicians who have unsurpassed experience in identifying and treating WTC-related illnesses. Previously, patients had to wait months to begin treatment; now that wait has been eliminated because physicians can prescribe much-needed medications during a monitoring examination. Perhaps most importantly, we are already working to put in place a system in place to monitor for so-called sentinel health events among treatment program patients.

The current working model is structured as a consortium of Clinical Centers of Excellence and a Data and Coordination Center – a model particularly well suited to dealing with unique medical conditions or unusual exposure situations in that clinicians gain unique expertise in dealing with affected patients. Similar models have been used by a number of federally funded programs with great success, including programs funded by the FAA, the Department of Energy, the National Security Agency, and the Department of Homeland Security. The WTC Program

Clinical Centers are located at Mount Sinai, Bellevue/NYU, SUNY Stony Brook, Mount Sinai Queens Hospital, and UMDNJ. They are staffed by clinicians with unparalleled experience in identifying and treating the conditions associated with exposures sustained following the attacks. The Data and Coordination Center is located at Mount Sinai, and it acts as a centralized clearinghouse of information by coordinating the activities of the Clinical Centers, facilitating the dissemination of best practices, and compiling and analyzing the data gathered during each examination. While there are other models of providing this care, we do not believe that they can ensure the same levels of clinical care and expertise of our current model.

The need for a permanent source of funding for ongoing monitoring and treatment for responders is clear. While private philanthropy has been an important vehicle helping to pay for treatment in the past, it is certainly not a sustainable solution. Some have proposed that we use solely private health insurance to cover the costs of treatment, but our experience with the Treatment Programs has indicated that this is also clearly not viable. The rates of uninsurance and underinsurance among those seeking treatment are already high and, as responders become more ill, they are likely to lose their insurance altogether. In addition, Workers' Compensation poses great obstacles for responders seeking timely treatment. In our experience, it can take years for a case to be established, and even then there are restrictive rules imposed on patients. For example, a patient in need of a sinus CT scan must, under the general New York State Workers' Compensation Law, get pre-approval because of the expense of the procedure. The pre-approval process can take months, effectively delaying the timely diagnosis and treatment necessary for adequate care. To date, the number of responders who have needed hospitalization has been relatively low, but we also expect this number to increase over time. Many responders are non-English speaking and their monitoring and treatment requires additional translation efforts, currently provided by these programs. Future program plans need also consider a potential diffusion of the responder population around the United States.

Because of the extremely complex and hazardous nature of exposures sustained following the attacks, we also expect to see new morbidities develop over time. While the exact extent of the health effects of WTC exposures is not fully known, it is known that responders were exposed to a wide range of toxins, including cancer causing agents and substances that can cause long term respiratory problems. For many patients in our program, the fears of future diseases like cancer, which can take as long as twenty to thirty years to develop, loom as large or larger than concerns about their acute ailments. It is absolutely essential that responders receive periodic standardized examinations for the rest of their lives to identify newly emerging conditions and to monitor the persistence of currently observed WTC-related conditions.

However, it is equally critical that monitoring be coupled with treatment which allows patients access to state-of-the-art diagnostic services and treatment by clinicians well-versed in the complex nature of WTC health effects and outcomes.

Five years following the attacks on the World Trade Center, thousands of the brave men and women who worked on the rescue, recovery, and clean up efforts are still suffering. Respiratory illness, psychological distress, and financial devastation have become a new way of life for many. I hope that my comments today will serve as a reminder of the long-term and widespread impacts of this disaster, and of the need for a continuous program which gives these men and women the care they deserve.

Thank you.